Comprehensive Transplant Center Patient Events

2010 Calendar

April 8
Transplant Patient Support Group. 7pm, Johns Hopkins Greenspring Station, Pavilion II, Lutherville, MD, RSVP to 410-614-5622 or visit our website. www.hopkinsmedicine.org/transplant

June 12
12th Annual Transplant Patient Conference. Located at the Crowne Plaza Hotel in Timonium, Maryland. This all day educational event is free of charge and open to all Johns Hopkins transplant patients, family members, and caregivers. Details will be mailed to patients in April.

December 7
CTC Annual Holiday Party. 6pm. Details on how to RSVP to this event will be mailed to patients in November. Information will also be available on the CTC website, www.hopkinsmedicine.org/transplant.

Unless otherwise noted, all events will be held on the East Baltimore Campus of the Johns Hopkins Hospital
The decision to write your donor family is a very personal and sometimes difficult decision. You likely have many questions and many apprehensions about whether or not you should reach out to this family.

**What should I say? When is the right time? Will they want to hear from me?**

These are all valid questions. Unfortunately, because the experience of grief and loss is a personal and unique one, there is no one right answer. What I can tell you for sure is, regardless of timing or content, the overwhelming majority of donor families do want to hear from you.

Many of these families chose organ donation because they want their loved one to be able to help another person and they want something good to come out of their tragedy. Often families are better able to heal because of the knowledge that their loved one was able to change a life. Hearing from you helps to reassure them that their loved one’s mission was carried out. The more you are able to share with them, the more they are able to understand just how much impact their loved one’s gift has had.

If you feel that you don’t have the words to say thank you for such a meaningful gift, don’t worry. It’s the fact that you are saying thank you that is important, not how you say it. Of course many families would love to hear about you and how you are doing, but if you aren’t ready for this, then a simple thank-you note is always appreciated.

Just the sheer effort of putting a letter or card in the mail lets them know that you are thinking of them and appreciate the difficult decision that they made. Don’t worry if you’re not a great speller or don’t use perfect grammar: the most memorable letters are the ones that come from the heart. As for the timing of your letter, we have families who are ready to communicate right away and families who want to wait longer. In general, 4-6 months is a good amount of time to wait. This gives both you and the donor family time to begin the difficult process of healing.

Please be assured that we always get permission from the family before forwarding a letter. If they are not ready for the letter, we will save it for them until they are ready to read it. Also, don’t be discouraged if you don’t hear back from the family right away. Not all families are ready to respond, but that in no way means they didn’t appreciate your letter.

- Eleanor Haley
Family Services Coordinator
The Living Legacy Foundation

If you want assistance with writing your note, card, or letter, please speak with your Transplant Coordinator or call the Family Services Coordinators at the Living Legacy Foundation at 410-242-7000.
From the Editor

Dear Friends,

If you were not able to attend the annual holiday party held in December we hope that you will be able to join us for one of our upcoming events.

The spring calendar is comprised of educational and social events that are designed for patients, caregivers, family, and friends.

Refer to the upcoming events section on the back page of the newsletter for more details!

Amy Schmidt
Transplant Outreach Coordinator

Bridges:
PATIENT NEWSLETTER OF THE JOHNS HOPKINS COMPREHENSIVE TRANSPLANT CENTER

Bridges aims to provide support for patients and their caretakers, to connect the CTC to its transplant family, and to inform patients about news within the transplant community.

Contributors to this issue include:
Antera Desai
Kate P. Knott, RN, BSN
Andrew Cameron, MD, PhD
Angie Muir, LCSW
Zeny Regalado, RD, LD
Eleanor Haley
Latrice Price

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Johns Hopkins Comprehensive Transplant Center,
2000 E. Monument Street
Baltimore, MD 21205
410-502-4379
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www.hopkinsmedicine.org/transplant

2010 U.S. Transplant Games

Team Maryland is busy preparing for the 2010 U.S. Transplant Games which will be held on the University of Wisconsin’s campus in Madison from July 30 through August 4, 2010.

Team Maryland is a group of transplant recipient athletes who compete in the U.S. Transplant Games, an Olympic-style athletic competition, presented biennially by the National Kidney Foundation.

One of the world’s largest gathering of organ transplant recipients, the U.S. Transplant Games allows athletes - kidney, liver, heart, lung, pancreas and bone marrow recipients - to compete for medals in 12 sports, including bicycling, bowling, golf, racquetball, swimming, tennis and track and field events.

In 2008, 20 athletes, 4 living donors and 2 donor families from Maryland attended the 2008 U.S. Transplant Games in Pittsburgh, Pennsylvania bringing home 11 medals, including three gold, four silver and four bronze.

As much as the Games are an athletic event that calls attention to the success of organ and tissue transplantation, it is also a celebration of life among recipients, their families and friends as well as an opportunity to honor the nation’s donors.

Team Maryland is always looking for new team members. Are you a transplant recipient, living donor or donor family member and are interested in attending the Games? Complete the on-line form at www.thellf.org or Contact Latrice Price, Team Maryland Manager at lprice@thellf.org or 410-242-7000 for more information.

Sporting Events:
Racquetball, Swimming, Table Tennis Tennis
Track and Field, Volleyball, Badminton
Ballroom Dancing, Basketball, Bicycling
Bowling, and Golf

Transplant Recipients are invited to make a square for the "Gratitude Quilt" in celebration of our organ and tissue donors and their families.

To find out more about the quilt project or to request a quilt square kit please call 410.502.4379 or email aschmi14@jhmi.edu.
Stepping Stones

I hope that many of you were introduced to Stepping Stones at this year’s CTC Holiday Party! For those of you who were unable to attend, Stepping Stones is a brand new fund that was developed by the Social Workers of the CTC. It is designed to help all adult post-transplant patients who are experiencing financial difficulty.

As Social Workers, we have an opportunity to work with patients throughout their transplant journey. We are often approached by patients who are experiencing financial difficulty of some kind – and with the current economic climate, the number of people struggling to keep up is only increasing. While it seems like there should be plenty of things that we can turn to and help people, the truth is, there really is very little. So the Social Workers of the CTC decided to come together and create our own resource, which we have named “Stepping Stones.” Through the use of parking coupons, gas cards, grocery cards and meal vouchers, we hope to:

1) Help remove barriers that affect a patient’s ability to keep up with post-transplant care
2) Help decrease stress for families of those hospitalized for an extended period of time
3) Help address the needs of those with extenuating circumstances

Funding for Stepping Stones will be dependent on donations and various fundraising events. At this year’s CTC Holiday Party, we hosted a raffle and bookmark sale as our very first fundraising event!

Thank you to everyone who helped with donations and those of you that bought tickets and bookmarks! Our first event was quite a success! 100% of the proceeds go directly to Stepping Stones and then directly to patient support! - Angie Muir, LCSW

Calling All Cooks and Bakers!!

We’re very excited about our next fundraising event for Stepping Stones – a CTC Cookbook! We know we have some great cooks and bakers among our patients and staff! Share your recipe and help us create our cookbook! Instructions and a recipe submission form are available online at www.hopkinsmedicine.org/transplant. You may also request a form be mailed or faxed to you by contacting Angie Muir at 410-614-4442.

Recipe Categories

Appetizers & Beverages
Soups & Salads
Vegetables & Side Dishes
Main Dishes
Breads & Rolls
Desserts
This & That

The deadline for recipe submissions is May 1, 2010!

Thank you for sharing your recipe and helping us create our cookbook!
Why do I need a Kidney Biopsy?

Why do you need a biopsy?
The most common reason is an elevation in your creatinine. A biopsy will help us determine if you have rejection. We may also want to do a biopsy to make sure your original kidney disease has not come back in the new kidney. This is most common with FSGS. On occasion we may biopsy to rule out a virus in your kidney.

At what point post-transplant can I expect to have a biopsy?
Any time during the life of your transplant, but it’s most common in the 1st year post-transplant.

Benefit of a kidney biopsy?
It’s the definitive way to figure out what is going on inside your transplanted kidney. Sometimes we don’t find anything, but a biopsy is the only way to make sure. It’s like looking at something you may want to eat, you can smell it & look at it, but you don’t know if it’s going to taste good until you take a bite.

**THIS IS NOTHING LIKE A NATIVE KIDNEY BIOPSY!**

The procedure
You CAN eat and drink and should take your medications as usual prior to your biopsy. **NOTE: IF YOU TAKE ASPIRIN OR PLAVIX YOU WILL BE ASKED TO HOLD THESE MEDICATIONS FOR A WEEK PRIOR TO THE BIOPSY.**

You will need someone to drive you home after the biopsy. A kidney transplant biopsy is an outpatient procedure that takes about four hours to complete. You will get labs prior to the biopsy, come to the biopsy area in the Nelson basement of the main hospital.

Once in the ultrasound area they will take your vital signs (blood pressure, temperature, etc.). The skin on your abdomen near your transplanted kidney will be numbed with a very small needle. The staff will put gel on your abdomen and glide a wand over the area to find your transplanted kidney (this is called an ultrasound, like pregnant women have done).

Once the kidney is found, the doctor will insert a fine needle and take a small bit of the kidney. No your kidney will not get holes in it like swiss cheese! The amount taken is the width of a pencil lead and less than one inch in length. The sample of your kidney then goes to the pathology doctors who look at your kidney sample under a microscope.

Recovering from the biopsy
You will need to lay on your side for two hours after the biopsy, during this time your vital signs will be monitored. We need to make sure you do not have any bleeding after the procedure or blood in your urine. Bring something to read or keep yourself occupied while you recover.

Complications
Bleeding is the most common which is why we monitor your vital signs, have you lay on your side and make sure that your urine is clear after the biopsy.

When will I hear about the results:
If you have rejection you are usually informed sometime during the evening. You may or may not need to be admitted to the hospital to treat the rejection. If you have not heard from someone by 9pm the night of the biopsy, you can call the transplant coordinator on call and ask for your biopsy results. The coordinator will then contact the transplant fellow for your results.

- Kate P. Knott, RN, BSN
Kidney Transplant Coordinator

Outpatient Procedure
You need someone to drive you home from the biopsy
Takes approximately 4 hours to complete
No restrictions in terms of returning to work the next day, lifting or eating.

Bring something to read or occupy yourself during the recovery.
Did I get a good Liver? Doing the right thing for our patients awaiting transplant....

Patients who need a liver transplant and are on the list waiting are in a dangerous position. The longer they wait the more chance they will succumb to liver failure and never make it to transplant or become so sick that their recovery is much longer and harder. If a patient develops a liver cancer it becomes a race against time to get a liver to do the transplant before the cancer spreads.

To make these life-saving transplants happen we need to use each and every donor liver we get offered that will give one of our recipients a good result.

What makes a donor liver a good one? For the most part, if a donor is younger (less than 55 or 60 years old) and is not overweight then we know that the liver will perform well for a long time and we don’t think twice. Sometimes, however, we get an offer for a liver from a donor who is 70 or even 80 years old.

Sometimes the donor may be overweight but have normal laboratory tests indicating good liver function. In these cases, what should we do? If we play it safe and declare that the liver offer is not up to our standards, a patient may die awaiting transplant. If we use every single liver we are offered no matter the donor we may risk hurting patients more than we help them if the liver doesn’t work well post-transplant.

The best solution is to go examine the liver ourselves. Studies have shown that the most accurate predictor of good liver function after transplant is the opinion of the donor surgeon when he or she looks at the liver at the time of procurement. If the color looks good, and the liver shows no sign of fatty infiltration, and the liver has a soft texture then the surgeon now knows it will be a good liver for transplant, even if the donor is older or obese.

It is sometimes difficult to go look at all the donors we get offered. Sometimes the donors are located in hospitals hundreds of miles away or require long travels in the middle of the night. But if we get a good liver for one of our patients that other centers thought they couldn’t used we have truly saved a life and done the right thing.

So the answer to the question “Did I get a good liver?” is always: “Yes, I guarantee it. I saw it with my own eyes.”

- Andrew Cameron, M.D., PhD
Surgical Director, Johns Hopkins Liver Transplant

MELD/PELD: Factors Used for Matching Livers to Patients Awaiting Liver Transplantation

The Model for End-Stage Liver Disease (MELD) and Pediatric End-Stage Liver Disease (PELD) are numerical scales used by the liver transplant community to match livers to patients awaiting transplantation.

The MELD score (for adults) and PELD score (for children) are based on how severe the patient’s medical condition is. The idea is to make sure that patients who are in most need of a liver transplant are identified to receive a transplant in time.

The range of the MELD score is from 6 to 40. As the score increases, the patient moves higher up the transplant list. MELD scores are determined using a mathematical formula based on serum creatinine, total bilirubin, and INR levels (in other words, the items measured each time liver patients get their bloodwork drawn pre-transplant).
My ability to cope with and tolerate the ventilator surprised everyone. I was more active, and my kidney and other bodily functions were slowly returning to normal levels as well. With the assistance of a respiratory therapist and a physical therapist, I was able to walk several hundred feet around the MICU using a portable ventilator unit, which was unusual as most intubated patients at this stage would be too weak for such physical exertion.

I was also not able to speak, eat or drink, and this was frustrating as I am a very talkative person; I started to communicate with doctors and family members with a pen and a notebook, and sometimes with a laptop. I was maintained in this manner for almost a week, when we were told early in the morning that a donor had been found and the transplant preparations had begun. Unlike many patients, I didn’t have to rush to the hospital as I was already there. And the timing couldn’t be more perfect; as fate would have it, we were in for another surprise.

I had developed a pneumothorax, a hole in my lung, and the ventilator pressures had to be reduced to keep my lungs from collapsing. Without the ventilator compensating for my cardiac and respiratory needs, my kidneys, liver and other functions began to break down; more than once, the nurse had to ventilate me using an ambu resuscitator bag. That afternoon I was taken to the operating room. Everyone was happy as well as nervous. As they wheeled me away on the stretcher to the operating room, I held both my thumbs up in the air; I was sure everything was going to be fine.

My operation lasted for 6 hours. The donor lungs were a little big for me as I am petite and they had to be shaved a bit to fit inside me. The surgery was a difficult one; I had severe fibrosis and my lungs had shrunk to a very small size and much of the scarring was against the thoracic wall, all of which had to be cleared before the donor heart and lungs could be inserted.

We had a few complications from the surgery itself; my liver had stopped working and they were unable to close my chest due to all the inflammation and size of the donor lungs. I was transferred to the Cardiac Surgical ICU (CSICU), where I remained for a few days and then taken into surgery once again for my chest to be closed. The liver functions thankfully returned the day after the first surgery, and my kidneys and other systems showed signs of improvement and normalized as well. With the positive turnout of the surgery, we were also glad that I was in no immediate risk for a kidney transplant.

Within a week of closing my chest, I tried walking with the portable ventilator. The first time was quite difficult to get up, but I managed to take three steps forward. As a physical therapist, I was disappointed by how weak I was and that I could hardly stand.

Each day I was able to walk farther and eventually I was walking up and down the CSICU corridor. Being a physical therapist myself I knew how important walking and exercise were for my recovery, and I always cooperated with my physical therapist and usually surprised them positively.

Initially, the doctors tried to wean me off the ventilator and extubated me on three different occasions to see if I could breathe on my own. Each time my CO2 levels rose and attempts were made to control that using a bipap machine, and when that failed they had to intubate me again. It was later found that the phrenic nerves that help move the diaphragm had been damaged as a result of the surgery, and this has caused some paralysis of the diaphragm; this also meant that my

Editors note: The following excerpt is written by Antera Desai, Heart/Lung transplant patient. The first part of Ms. Desai's story was featured in the Spring/Summer 2009 edition of Bridges. Visit www.hopkinsmedicine.org/transplant to view the entire article.
recovery and strengthening would take a great deal longer. This was a source of tremendous frustration and disappointment for me, as I had high expectations of breathing normally, leaving the hospital within weeks of the surgery, learning to dance and possibly run a marathon, like the other transplant patients I had heard so much about.

Given that my recovery was going to take longer than we had expected, staying intubated for a long recovery period was not a good option; as this placed me at a higher risk for infection. I received a tracheostomy so the ventilator could be attached at the bottom of my throat; this was safer as the inner cannula of the trach site could be routinely replaced. I had also gone without nutrition for several days since before the surgery, and I had lost a considerable amount of body weight and muscle mass. I was growing weaker, and as I could not eat while on the ventilator, I was given a PEG tube in the stomach and given regular tube feeds. The trach and the PEG would be my air and food sources for the next several months as my body strengthened.

After a month in the CSICU, I was moved back to the step-down unit to continue my recovery process. It was a difficult road ahead of me. I was impatient and frustrated that I needed a ventilator in this new chapter of my life. The doctors tried to wean me off gradually, by moving the ventilator settings from full-support to pressure-support, and it was quite difficult to stay on pressure-support as this forced my lungs to do most of the work. My doctors, nurses, and family would push me to stay on pressure-support for as long as possible, as it was necessary for me to build a tolerance and without a functioning diaphragm.

Between the breathing, the ventilator-assisted walking and physical therapy exercises, I would tire easily. As I pushed to stay off full-support for longer periods of time, I started to have severe anxiety attacks. The process of lying flat would also trigger these attacks, as it is extremely difficult to breathe lying flat without a working diaphragm.

In discussing and working with a psychiatrist on the transplant team, and a low assistive dose of anti-anxiety medication, I received the much needed help to overcome these attacks. A month later, I was able to use a trach collar without any ventilator support. The trach collar would blow either room air, or oxygen, or both, and allowed for greater mobility. My nurses were now able to take me outside the hospital ward, so I could smell and breathe the fresh open air. This was good sign that I was strengthening and added a greater confidence to my recovery.

I also passed a swallow test that would check if I would be able eat regular food or swallow pills without aspirating. After three months of not eating, it was wonderful to be able to eat my favorite fruits and dishes again. The final test was the use of a speaking valve, which would partially close the trach entrance and forced me to breathe using my nose and mouth; this also allowed my voice to be heard. Using the speaking valve was quite tiring at first, and it seemed as though I had taken a step back and was learning to breathe again.

As I built up my tolerance for the valve, the doctors began to change the trach to its fenestrated versions that allowed for more air from my nose and mouth to pass through; the changes made it much easier for me to speak and I could feel that it was easier for me to breathe as well. I was finally decannulated and the entire trach was removed; this was a big step for me, but I had to continue using a bipap at night to make sure that I gave my lungs as much rest as possible so that I could use them for longer periods during the day. Within a week of my decannulation, and this was three months after surgery, I was discharged from the hospital.

When I look back at this last year and all that I have been through, these have been the toughest days of my life, but they were worth going through. I feel a hundred times better than I did before my transplant, and I wish I had gone through my transplant earlier. It has made such a drastic change in the quality of my life.
Nutrition and Lung Transplantation

Lung Transplant surgery becomes necessary when a patient has end-stage disease that is no longer responsive to medical therapy.

Approximately 11,000 lung transplants have been done in the United States. Most common indications for lung transplant surgery are: chronic obstructive pulmonary disease (COPD), Cystic Fibrosis (CF), Idiopathic Pulmonary Fibrosis (IPF), or Pulmonary Hypertension.

Malnutrition associated with COPD is widely published focusing on lean body mass and fat free losses.

IOF is a very aggressive disease with patients’ survival time of 3-5 years after diagnosis. The nutritional goal for these patients is to maintain adequate nutritional intakes to promote nitrogen balance, adequate fat free mass, and a health weight to support functional capacity while awaiting transplant surgery.

Complications that can limit nutritional intakes among CF patients are – acid reflux possibly inducing esophagitis, CF related diabetes, distal intestinal obstruction syndrome, and anorexia associated with depression and advanced respiratory problems. Maximizing nutritional status and exercise capacity to preserve and build lean body mass is the priority for patients awaiting lung transplant surgery.

Eating involves use of many muscles in patients with lung disease. They require more energy from foods because of their increased work of breathing. When nutritional requirements are not met, weight loss occurs.

Malabsorption and nutritional losses occur in CF patients due to pancreatic insufficiency, bile salt losses, and thick intestinal mucus. Pancreatic enzymes are taken with meals and snacks to maximize nutrient absorption. Vitamins and nutritional supplements are addressed and monitored among these patients.

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Obesity complicates breathing by increasing respiratory muscle needs for oxygen and results in decreased performance. Obese patients should be referred to weight loss management programs while awaiting transplant surgery.

Appropriate alterations in mean size and frequency and some medication may help lessen symptoms associated with poor oral intakes such as shortness of breath, decreased oxygenation, and breathing.

Special nutritional support may be necessary via tube feedings or parenteral nutrition if a patient is unable to eat by mouth secondary to prolonged intubation or other complications after surgery.

The long term goal of nutritional therapy for lung transplant recipients is directed towards management of comorbid conditions such as obesity, diabetes, hypertension, and hyperlipidemia.

With comprehensive nutritional assessment and knowledge of nutrition related issues as well as close monitoring by the lung transplant team physicians, nurses, social workers, physio and occupational therapists, and dietitian, survival and quality of life for these patients can be optimized and maximized.

- Zeny Regalado, RD LD

Sample Menu...

Eating a well-balanced meal means eating a variety of foods from all food groups.
Do not skip meals. Rest before eating and choose foods wisely. Eat small but frequent meals.

**Breakfast**
1 cup whole grain dry cereals
1/2 cup fresh fruit
1/2 skim milk or 2% milk
Coffee or Tea

**Lunch**
1 cup mixed green salad with 1 tsp. low fat dressing
Cold Sliced Turkey - 3 slices
Whole Wheat Bread - 2 slices
1 tsp. Mayonnaise
1/2 cup fruit jello with low fat whipped cream
Water/ Iced Tea

**Dinner**
Baked Salmon, 3-4 ounces
1/2 cup spinach/sliced lemon
3 tomatoe slices
1-2 small boiled potatoes - 1 tsp. margarine
1/2 cup low fat parfait or 1/2 cup fresh fruit cup
Coffee or Tea
Returning to Work after Transplantation

As you recover from surgery and begin to adjust to living with a transplant, it is natural to start thinking about the future. You may begin to think about returning to work. This is exciting but can also be scary, especially if you have not been able to work for a long time because of your health.

The decision to go back to work can be complicated. For one, you may feel better but not 100% and may be uncertain if you can manage to work. You might worry that you cannot be dependable due to your health care needs. You may be concerned about jeopardizing your transplant and current state of health. You may think that your skills are obsolete or be nervous about fitting in. You may feel that they won’t hire you because you had a transplant. It is normal and natural to feel a wide variety of emotions when making a life change. Returning to work takes thought and planning.

First, if you have been receiving Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI), you must educate yourself as to how working will affect your benefits and federal or state health insurance coverage. Disability status is routinely reviewed by Social Security. Transplant is considered a disability for 12 months following surgery. Social Security will review your case at that time to determine if you are still eligible for benefits. If you qualified for disability only due to organ failure, you may no longer be considered disabled. Remember, SSDI and SSI eligibility are based on being unable to work ANY job, not just the job you used to have. Of course, if you are considered disabled due to other health issues or symptoms, you will continue to receive Social Security payments. You must talk to Social Security or Social Services prior to returning to work to understand how working will affect your benefits. For more information: www.ssa.gov/work/

There are many ways to ease back into the working world. One is to start slowly with part time work, working for friends or family, or volunteering. Another way to bridge the gap between disability and working is by utilizing State Vocational Rehabilitation programs. This article will focus primarily on Maryland’s program, but programs exist in most states.

DORS is the Division of Rehabilitation Services. This is a public rehabilitation program that helps people with disabilities become employed or stay independent in their homes and communities.

Who is eligible for DORS services? If you receive SSI or SSDI you will be eligible. If you have a significant physical, mental or cognitive disability that affects your ability to work, and you require services in order to be able to work, you may qualify for DORS services. Funding for services is limited so people with the most significant disabilities are served first.

Another alternative available to patients who may not be able to return to work is returning to school. Taking advantage of programs offered at your local community college can be an ideal way to jump start your new life.

Don’t forget, before you begin the return to work or school you must first talk to your transplant coordinator and physician to get the OK to return to work and to make sure the work you wish to do is safe for transplant. A new and bright future awaits!

Mary Kaiser, MSW, Kidney/Kidney Transplant Social Worker

Helpful Websites...

DORS, Maryland
Main Phone: 1-888-554-0334
Baltimore City: 410-554-9442
www.dors.state.md.us

Maryland Community Colleges
www.mdacc.org

Maryland Higher Education Commission
www.mhec.state.md.us

Maryland Workforce Exchange
https://mwe.dllr.state.md.us/

Maryland Public Libraries
www.publiclibraries.com/maryland
12th Annual Transplant Patient Conference

On Saturday, June 12, 2010 the CTC will host the 12th Annual Transplant Patient Conference. The event will be held at the Crowne Plaza Hotel located in Timonium, Maryland.

Our annual conference has become a staple for many of our patients and we look forward to welcoming you back. For those of you who are new to Johns Hopkins and transplantation, we encourage you to join us for this free of charge, daylong event.

We are excited to announce that our keynote speaker will be Ms. Pamela Paulk. Ms. Paulk donated her kidney to a coworker in the Summer of 2009. Currently Ms. Paulk is the Vice President for Human Resources for the Johns Hopkins Health System and The Johns Hopkins Hospital.

We will be highlighting the importance of living donation at this year’s conference. We will be offering a session dedicated to living donation and the options patients and potential donors have available to them.

We will also be highlighting the importance of having a caregiver immediately post transplant and beyond. Angela Muir, LCSW, social worker for the CTC will be leading this session.

Ms. Muir will be restructuring this session to include personal stories from actual caregivers. This session will also provide caregivers with the knowledge of services available to them.

Finally, we are pleased to offer the 2nd Annual Transplant Liaison Educational Program at this year’s conference. This program is designed for employees of dialysis units. The purpose of the program is to better educate dialysis units on the procedures of the CTC.

This conference is open to all transplant patients, pre and post, as well as living donors, family members, caregivers, and healthcare professionals. The conference is completely free of charge as is parking.

We will be sending information in the mail regarding the conference in April. If you have any questions please contact Amy Schmidt, at 410.502.4379 or aschmi14@jhmi.edu.

**DRAFT AGENDA**

**Keynote: Pamela Paulk, Living Kidney Donor**
Vice President for Human Resources for the Johns Hopkins Health System and The Johns Hopkins Hospital
9:00 - 9:45am

A1. Living Donation 10:00am - 10:45am
A2. Nutrition for Liver and Kidney patients 10:00am - 10:45am
A3. Deciphering the Liver Wait List 10:00am - 10:45am
A4. Caring for the Caregiver Seminar 10:00am - 10:45am
A5. Deciphering the Heart and Lung Wait List 10:00am - 10:45am

B1. Liver Transplantation 11:00am - 12:00pm
B2. Heart/Lung Transplantation 11:00am - 12:00pm
B3. Kidney Transplantation 11:00am - 12:00pm
B4. A Patient’s Role After Transplantation 11:00am - 12:00pm

C1. Transplantation from a Patient and Caregiver Perspective 1:00pm - 1:45pm
C2. Preventing Skin Cancer 1:00pm - 1:45pm
C3. Deciphering the Kidney Wait List 1:00pm - 1:45pm
C4. Preventing Infections (MRSA, CMV, etc.) 1:00pm - 1:45pm
News and Notes

At the ten year anniversary of her liver transplant, the family and friends of Patricia ("Pat") Barget, generously donated money to the CTC to honor the life of Pat’s organ donor, Clare Furay. The donation honoring Clare provided support for the Transplant Holiday Party: “A Celebration of Life” which is attended by donors, patients and their families along with Hopkins staff. Says Pat, “It was a wonderful way to mark the goodness of humanity to care enough about another, even another who is a stranger, to give the gift of life in the midst of intolerable grief.”

The following is a brief description of Pat’s experience knowing her donor family, 10 years after the transplant.

For my 10 year transplant anniversary, my family and I re-initiated contact with the family of my organ donor, Clare Furay. In their correspondence, the family had sent us a collection of Clare’s writings and musings from throughout her life, as she grew up as one of nine children, graduated from Notre Dame, served in the Navy and worked with the homeless as a Jesuit Volunteer Corps in Baltimore in preparation for law school. It was then that I truly began to have a deeper understanding of my donor and her family.

In the prologue she wrote this about herself: “Three things define me. Without any one of them, I would cease to be Clare Furay. My joy exists in these three things, and they sustain me. They are my family, my search for faith, and my writing. I do well to love these things. I do well to invest myself into them. I know this as simply and surely as I know I have green eyes.”

Clare Furay, Journal entry, 1998

Today, as a recipient of a liver transplant, I am healthy and happy. I have had the gift of these ten years in which I have been given 6 wonderful grandchildren, witnessed three marriages of my children and had the freedom to enjoy my life and go where I want.

Through Clare’s book, I learned that she was a unique and gifted young woman who had generously shared her life’s energy through giving of herself, her time, her thoughts and growing wisdom. I keep Clare’s book beside my bed. She is the last to bid me goodnight and the first to greet me for each exciting new day.

- Jeanni Hines
Daughter of Pat Barget

Generic Medication vs. Name Brand

Recently one of the medications you may be taking to prevent rejection of your transplanted organ, Prograf/Tacrolimus/FK506, has been made available in a generic preparation. This follows the generic availability of Cellcept/ Mycophenolate Mofetil made earlier last year. This is a normal process but infrequent when it comes to these types of medications. We are certain that the possibility of you being prescribed or directed by insurance to these new generic medications may present you with a number of questions and decisions.

The Johns Hopkins Comprehensive Transplant Center multi-disciplinary team has sent out a letter to all post- transplant patients to help you understand these changes. If you have not yet received your letter please be patient as we are in the process of sending them out.

Please feel free to contact your post-transplant coordinator with any questions, concerns or help in further understanding the options of generics.